

Condition Insight Report (CIR)

Nystagmus

VERSION 1.0

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Completed in collaboration with
RNIB

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Overview

What is the condition usually called / any abbreviations used?

Nystagmus

Brief overview of the condition

Nystagmus is a constant and uncontrolled movement of the eyes (can be described as a 'wobble'), which affects how clearly someone can see. Most people with nystagmus have reduced vision.

Nystagmus causes the quality of vision to be reduced and, depending on the cause, the level of impairment varies from person to person. Some people have severely reduced vision and some have minimal impact. The variability is due to the range of causes of the condition.

There are two main types of nystagmus:

- **Congenital nystagmus**, infantile or early onset nystagmus are caused by an interruption to the normal development of vision before or shortly after birth (albinism, aniridia, Down's syndrome, retinal dystrophies, coloboma are a few possible causes, although many cases are idiopathic i.e. no known cause).
- **Acquired nystagmus** is caused by something that happens after birth, usually in adults, such as head trauma, brain cancer, brain inflammation such as in MS, or stroke.

What is the generally preferred term for someone with this condition?

An individual with nystagmus.

Presenting Symptoms

Main symptoms include, but are not limited to:

- **Noticeable wobble of their eyes**: this is usually side to side jerky movement but can be up and down or circular (rotational).
- **Abnormal head posture** so that they can utilise the best direction of gaze.
- For example you may find the wobble increases on left gaze but is at a minimum (called the null point) on right gaze.
 - They may not be able to hold eye contact.
- If the room lights are bright, such as halogen spot lights or lights without diffusers, they may need to **wear glare shields**.
- Nystagmus gets worse when one eye is covered and improves if both eyes are being used together and have the best possible spectacle or contact lens correction.

Some people with congenital nystagmus will suffer from disability glare (glare that reduces vision). If their eye condition is caused by **ocular albinism** (*a genetic condition that reduces the colouring of the iris*) or **aniridia** (*an eye disorder characterized by a complete or partial absence of the coloured part of the eye*) and some other childhood developmental conditions. This will mean that any task that is outdoors will be significantly more difficult to do. They are not usually aware of movement in their vision.

Nystagmus may also have a **psychological impact** as well as a visual impact.

How is it diagnosed?

Nystagmus is generally diagnosed by an Ophthalmologist completing a Videonystagmography (VNG).

How does it feel to live with Nystagmus?

A claimant may feel like their eyes "**Have a mind of their own**". The eyes move up and down, side to side, or in a circle. This is often called "dancing eyes." It's a condition where you can't control your eye movements.

Useful information to know

Watch **Phil** talk about his experience of living with Nystagmus **[HERE](#)**.

What treatment is there?

Nystagmus cannot be cured, however, contact lenses and glasses can improve the symptoms and sufferers can also be given eye exercises to reduce movement.

Nystagmus COMMON WARNING SIGNS



Uncontrollable eye movement



Nighttime vision problems



Shaky or blurry vision



Balance problems



Light sensitivity



Dizziness

 Cleveland Clinic

Reliability

What specific areas should be covered to ensure a complete, reflective report?

S  **AFETY**

Do they have any symptoms which could cause a safety consideration?

It is important to explore safety and how they manage their sensory loss especially in activities 1, 3, 4 and 11. Uncontrolled eye movement could lead to them dropping things or misjudgement of objects and such cause a risk.

T  **IMELY**

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

Nystagmus causes people to need longer to focus on things, so they may take longer to read or see things.

A  **CCEPTABLE STANDARD**

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Individuals will compensate for the sensory loss in different ways and it needs to be clearly explored to determine whether it is acceptable management within PIP and how this might be classified e.g. an aid, supervision or assistance.

R  **EPEATEDLY**

Are they able to repeat a task as often as required? Is this the same every day?

In some tasks it is not possible to keep your head and direction of gaze to an optimum and therefore the vision will be worse for some tasks than others. Also, visual acuity can be significantly worse when someone is stressed, tired, unwell or anxious, or when they can't control the light levels or when the task requires a specific direction of gaze.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

They may struggle to maintain their null point to be able to manage temperature gauges, manipulation of items, especially whilst chopping, which will impact their ability. This cannot always be mitigated with aids.

Remember in PIP...

Can they safely complete this activity? Have they attempted to use aids before? Can they cut vegetables or see a flame on the hob? Have they had any incidents in the kitchen? Do they require assistance?

Activity 2: Taking nutrition

Many are likely to be independent with this task but this will depend on how they are/have adapted to their sensory changes.

Remember in PIP...

As nystagmus causes uncontrolled eye movement, they may drop food. You must establish if this does happen, how often? How do they mitigate this?

Activity 3: Managing therapy and monitoring a health condition

Consider if the claimant has medication for other conditions, the nystagmus may impact their ability to manage this.

Remember in PIP...

Ensure to explore how they manage their medication. Can they reliably establish what their medications are? Can they get it out of the packet and self-administer? If not, why is this and how do they overcome the restriction?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and bathing

Sight loss in a wet environment can be challenging for many and they will manage this in different ways. Some may rely on aids to guide them and keep them safer in this environment, others may not require this.

Remember in PIP...

We must consider everyone's ability to transfer in and out of an un-adapted bath, even if they only have a shower. As nystagmus may impact balance, you must explore how the claimant gets in and out of the bath safely.

Activity 5: Managing toileting needs and incontinence

There is no physical limitation unless there is a co-morbidity, however, many people will have different ways to manage their sight in this environment.

Remember in PIP...

Within the scope of the activity, we must know;

1. How the claimant transfers on and off the toilet.
2. How they manage to clean themselves.
3. If they have any incontinence, if this is majority of days, and if this is self-managed. (Remember if incontinence is self-managed this would still be considered an aid within the scope of the activity.

Activity 6: Dressing and undressing

Sight impairment secondary to nystagmus may impact the claimant's ability to establish if clothes are clean.

Remember in PIP...

If there is evidence of a visual impairment, we must establish how the reported restriction is being overcome, if at all.
For example, we would expect someone with a longstanding visual impairment and no cognitive difficulties, to be able to establish if clothes are clean or dirty.
Explore if they have any techniques to separate clean and dirty clothes.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating verbally

Comorbidities should be considered as visual loss is unlikely to impact speech.

Remember in PIP...

As nystagmus is unlikely to directly impact this activity, try and remember the scope of the activity in general. The claimant needs to be able to both **express** and **understand** complex verbal information. PIPAG would suggest complex verbal information is information conveyed in either more than one sentence or one complicated sentence, for example: "I would like tea please, just a splash of milk and no sugar, as I always have sweeteners with me for when I go out."

Activity 8: Reading and understanding signs and symbols

Typically, a person with congenital nystagmus may have difficulty with reading small print, however, this can sometimes be improved with glasses or contact lenses.

Remember in PIP...

Any visual restriction or comprehension restriction will need to impact their ability to read on the majority of days. Remember, the PIPAG suggests that the distance between the eyes and written material is not relevant. However, we would need to consider if the claimant has any aids to assist with this activity or if they need assistance. What can they read and how do they overcome their restriction?

Activity 9: Engaging with others face to face

The condition also makes it hard to make eye contact with others, often making social situations awkward for them. Dealing with this element of the condition causes some people to avoid public situations and limit going out or socialising.

Remember in PIP...

Cover where specific restrictions are reported how they manage this. Detail of any support provided and whether this support can be provided by anyone or only specific individuals.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

The ability to manage this will be different for each individual.

Remember in PIP...

Ability to see coins is not considered within the scope of the activity, neither is reading household bills.

Explore their cognitive ability to manage household finances, future purchases and change in a shop.

Activity 11: Planning and following a journey

Nystagmus can cause difficulties with spotting things in a crowded or moving environment and can make judging distances and speed of objects difficult (crossing roads and navigating in crowds. Some people with congenital nystagmus will suffer from disability glare (glare that reduces vision) if their eye condition is caused by ocular albinism or aniridia (and some other childhood developmental conditions). This will mean that any task that is outdoors will be significantly more difficult to do. They are not usually aware of movement in their vision. They are unlikely to be eligible to drive due to the oscillopsia effect.

Remember in PIP...

Ensure you explore the claimant's ability to safely navigate when out of the home with their visual impairment. Can they navigate curbs? Can they safely cross the road? How would they manage a diversion? Do they have any orientation aids or require assistance to go out of the home? If they have adapted, would this be considered reliable within the scope of PIP.

Activity 12: Moving around

This will depend on an individual's comorbidities.

Remember in PIP...

Remember that any safety due to their sensory loss will be covered in A11, here you should seek to determine if there are comorbidities which affect their physical ability to move around on flat surfaces and management of kerbs.

Additional reading or other resources

EXTERNAL

- <http://www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/nystagmus>
- <https://www.gosh.nhs.uk/medical-information/nystagmus>
- <http://nystagmusnetwork.org/>
- <https://www.mstrust.org.uk/a-z/nystagmus>

INTERNAL

- Desktop Aid – Vision, Activity 11
- **Visual and Hearing Impairment CPD Module.**

Version control